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NATIONAL COMMISSION ON AIDS

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COMPLETED

Report Number Two:

Leadership,
Legislation and
Regulation

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**NATIONAL COMMISSION ON
ACQUIRED IMMUNE DEFICIENCY SYNDROME**

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April 24, 1990

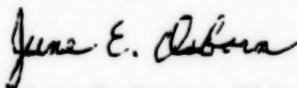
President George Bush
The White House
Washington, DC 20500

Dear President Bush:

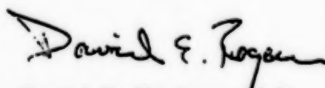
We much appreciated your meeting with us on March 29 and your historic speech that same day.

In our continuing effort to bring important and urgent matters to your attention, and to the attention of Congress, enclosed is a second report on the HIV epidemic from the National Commission on Acquired Immune Deficiency Syndrome (AIDS). Again, it contains a short series of recommendations for swift action.

Sincerely,



June E. Osborn, M.D.
Chairman



David E. Rogers, M.D.
Vice Chairman

cc: The Honorable Robert C. Byrd
President Pro Tempore of the Senate

The Honorable George J. Mitchell
Majority Leader of the Senate

The Honorable Bob Dole
Minority Leader of the Senate

The Honorable Thomas S. Foley
Speaker of the House of
Representatives

The Honorable Richard A. Gephardt
Majority Leader of the House of
Representatives

The Honorable Robert H. Michel
Minority Leader of the House of
Representatives

NATIONAL COMMISSION ON AIDS

Report Number Two

INTRODUCTION

On December 5, 1989, the National Commission on AIDS wrote to President Bush indicating that "significant changes must be made not only in our health care system but in how we think about the system and the people it is designed to serve." It was also the Commission's belief that a clear statement from the President indicating that in this crisis, care must be dispensed equitably, non-judgmentally, and without discrimination to all who had AIDS and HIV infection would do much to improve the climate and permit swifter progress in combatting this tragic epidemic.

On March 29, 1990, in a speech to a national meeting of business leaders the President responded to the Commission's call. In it he said:

"And for those who are living with HIV and AIDS, our response is clear: They deserve our compassion. They deserve our care. And they deserve more than a chance—they deserve a cure.... In this Nation, in this decade, there is only one way to deal with an individual who is sick. With dignity, compassion, care, confidentiality, and without discrimination."

In addition to establishing a national standard for caring for people living with HIV infection and AIDS, the President outlined the challenges confronting all of us in the HIV epidemic.

"It is our duty to make certain that every American has the essential information needed to prevent the spread of HIV and AIDS. Because while the ignorant may discriminate against AIDS, AIDS won't discriminate among the ignorant."

"Once disease strikes --we don't blame those who are suffering. We don't spurn the accident victim who didn't wear a seat-belt. We don't reject the cancer patient who didn't quit smoking. We try to love them and care for them and comfort them. We do not fire them, or evict them, or cancel their insurance."

We congratulate the President on his important and historic statement. It sets the stage for expansion of efforts of critical importance if we are to genuinely contain the spread of the HIV epidemic. His call for more preventive education, vaccines and new therapies to improve the care for the increasing number of Americans who will fall ill with this disease moves this nation in the proper direction. Now the President's commitment needs translation into action.

Since 1981, more than 75,000 people have died of AIDS and the 1990's will be much worse than the 1980's. This second report from the National Commission on AIDS to the President and the Congress highlights another set of critical issues and focuses on the particular needs of communities most heavily impacted by the epidemic. It contains an additional five recommendations for swift action.

■ OVERVIEW

"Much in AIDS care is happening all over this nation. But like an orchestra without a conductor, we are all playing our own tune. Sometimes we harmonize, sometimes we don't.... It's pretty tough without a conductor."

This quote is from National Commission Member Diane Ahrens summarizing the testimony the Commission received at a Working Group Meeting in St. Paul, Minnesota. The call for leadership in response to the Human Immunodeficiency Virus (HIV) epidemic was heard repeatedly during the Commission's hearing in Southern California and again during our visit to New York City's homeless shelters and New Jersey's hospital and drug treatment programs.

We were told, "Governments must assume leadership in this crisis," and, "Leaders often must take unpopular stances and try that which has not been tried." And, we were reminded that Thomas Jefferson once said, "The care of human life and happiness is the first and only legitimate object of good government." The President's speech was an important initial step in this direction.

COMMISSION FINDINGS

Nowhere was it more evident that the care of human life must be a priority for our government than in the streets of New York City. Here the estimates of the numbers of homeless vary from 20,000 to as many as 70,000. It is further estimated that 20 to 30 percent of the overall number of homeless individuals are HIV positive. Perhaps 10,000 have AIDS or HIV-related illness. They live in places that are beyond belief in their horror. We heard that the number of homeless in New York City now exceeds the number seen at the height of the great depression. "The new Calcutta" is a term now often applied to this, our premier city.

On February 26th, the Commission visited a variety of homeless "shelters"—ranging from subway tunnels to flophouses to an aging armory. At the armory, which can really best be described as a human warehouse, we stood on a balcony and saw stretched out below us nearly 900 tightly packed cots in a gloomy, cavernous old building. Each night the cots are filled with homeless men. The very great likelihood is that many of those huddled there (we

visited on the coldest night of the year) were infected with HIV. While we were there two homeless men, showing their positive tuberculin skin tests to us, voiced their concern that -- "people who are extra-susceptible to infections should never be sleeping in a place like this!"

Fort Washington Armory was not the only human catastrophe we witnessed. During our travels we heard about families not only broken but kept asunder by rigid visitation rules for addicted mothers --even those under treatment. We met women with HIV infection who sleep in shelters during the night and struggle to maintain their health (and their children) on the streets and in the shelters during the days. We heard about a supportive housing program that funds only 140 units when at least 2,400 could be filled immediately. We talked to teenagers who trade sex for drugs and money, putting themselves at risk for HIV infection everyday. Now referred to as "throwaway kids," these teenagers seek shelter not only from the cold but from the Hudson River piers and neighborhood streets where adults visiting from out of town, out of state, and, in some cases, out of the country, seek sex for \$15 without a condom and \$10 with one.

We met with outreach workers who go down into the subway tunnels day after day fighting a battle where they have no ammunition and, indeed, no battlefield on which to stand. The outreach workers hope that one day the "down under" people will come to one of the day programs offered in the Bowery where they can receive medical assessment, treatment and referrals. "Many homeless people are suspicious of promises made for better lives," staff of the Bowery Residence Committee (BRC) told the Commission. "Too often these promises have been broken." In fact, the promise of health care for many of the homeless HIV-infected population in New York's Bowery will be further delayed if, as we were told, the federal dollars are terminated.

In California, New York and New Jersey, we heard repeatedly about the "disaster relief" needed from the federal government for those cities hardest hit by the epidemic.

In Los Angeles, the Commission was deeply troubled by the hamstringing restrictions on the use of public dollars imposed by the elected local officials. Here local decision makers are prohibited from initiating the very efforts that could prevent further spread of the epidemic in a county with the second highest number of reported cases of AIDS in the United States.

In some areas of California there is absolutely no outpatient care available to people with HIV infection and AIDS. In yet other areas, there are six to eight week waits for outpatient services. "Outrage," the Commission was told, "is the only morally credible response."

In February of 1990, the Commission visited a drug treatment program in Northern New Jersey. We were told that, this year, New Jersey received in excess of \$6 million in federal funds to reduce its waiting list for drug treatment services. New Jersey created more than 1,000 new treatment slots with the funds, but the Commission was told these funds will run out at the end of September. When we asked what drug treatment programs would do when the one-year-only federal dollars run out the response was, "Serve more with less—just like we always do." New Jersey ranks fifth among the states in its reported number of AIDS cases and first in its proportions of cases among intravenous drug users, minorities, women and children.

Across the country, the Commission also heard tales of health care denied unless it required acute hospitalization, and we heard desperate pleas that something be done to insure that all hospitals participate equally in provision of under-reimbursed AIDS care, rather than continue the grossly disproportionate distribution resulting from the subtle "patient dumping" now apparently practiced all too frequently in too many parts of the country.

SUMMARY

A lack of clear definition of government roles at all levels has hampered our national ability to organize health care services, to recruit

and train human services personnel, to provide housing for the sick, to provide effective AIDS education and prevention programs, to provide coordinated, comprehensive substance abuse treatment and prevention and to develop sufficient monies to finance all of these efforts. All across the country there is a cry for leadership from the federal government and partnership between the different levels of government. There is no question that there have been creative and often heroic efforts at every level of government to address the HIV epidemic, but coordination of these efforts is the missing link to an effective national strategy.

We are increasingly convinced that one set of actions recommended in our first report must be swiftly implemented. A national plan, with clearly delineated responsibilities and agreement on the roles of federal, state and local government and the private sector is essential and long overdue. If we are to respond effectively to the HIV epidemic we must have a clear cooperative plan and make responsible use of the limited dollars available.

The National Commission on AIDS, therefore, makes the following recommendations:

- 1.** The National Commission on AIDS will continue to recommend policy goals for a national plan. However, the Commission believes it is essential that a federal interagency mechanism be in place to coordinate a national plan. In this way, those who are ultimately responsible for the implementation will have an active role in its development.
- 2.** Federal disaster relief or direct emergency relief is urgently needed to help states and localities most seriously impacted to provide the HIV prevention, treatment, care and support services now in short supply. The Commission strongly supports the efforts in Congress, now embodied in S.2240, to address this need. The resources

simply must be provided now or we will pay dearly later.

3. Housing is an absolutely vital component of any comprehensive effort to address the multiple problems posed by HIV infection and AIDS. While the Commission recognizes that coordination between the state and local government, with input from community based organizations, is essential to effectively respond to the homeless crisis, we also believe the federal government must take the lead in providing the dollars needed to respond to this overwhelming, indeed catastrophic, problem.

4. Government restrictions imposed on the use of education and prevention funds are seriously impeding HIV control. They are clearly serving to prolong the HIV epidemic and should be removed.

5. Because the Americans with Disabilities Act (ADA) guarantees protection against discrimination for people with HIV infection and AIDS, the National Commission on AIDS strongly urges the U.S. House of Representatives to pass the ADA in a swift and timely manner. State and local governments should pass laws forbidding discrimination in areas not covered by the ADA or other federal statutes.

END

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